**Additional file 1: Table S1.** Survey questionnaire for TSC caregivers/families

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| **Questions** | **Choices presented** | |
| 1) Have you/the patient ever had a mental health/neurocognitive assessment, or filled out a TSC-Associated Neuropsychiatric Disorders checklist? | * No * Once (ever) * Once every 3 years | * Once a year * Twice a year * Every 3 months |
| 2) Do you feel that your/the patient’s psychiatric/neurocognitive requirements were appropriately managed by the physician? | * No * Somewhat | * Mostly * Yes |
| 3) Who/what raised the issue of TSC-Associated Neuropsychiatric Disorders (mental health or neurocognitive issues) with you/the patient? | * You/family member * Teacher * Rehabilitation professional * Physician | * TSC specialist * A screening process * Other (please specify) |
| 4) How easy is it for you/the patient to obtain a psychiatric assessment, if required? | * Easy * Difficult | * Very difficult * Not required |
| 5) How long have you/the patient been on a waiting list before being seen by a TSC specialist? | * 0 – 3 months * 3 – 6 months * 6 – 9 months | * 9 – 12 months * > 12 months |
| 6) How easy is it for you/the patient to obtain continuing psychiatric therapy, if required? | * Easy * Difficult | * Very difficult * Not required |
| 7) How effective do you consider the collaboration between your/the patient’s mental healthcare team, and the rest of your healthcare team to be? | * Ineffective * Somewhat effective * Mostly effective * Very effective | |
| 8) How does it feel for you/the patient to be referred for psychiatric assessment/treatment, compared with other healthcare assessment/treatment? | * The same * More negative * More positive | |
| 9) Answer (a) or (b) as applicable:   1. If you/the patient has not previously received psychiatric treatment for TSC: Do you think that psychiatric treatment could improve the quality of life for TSC patients and their families? 2. If you have/the patient has previously received psychiatric treatment for TSC: Do you think that psychiatric treatment can improve the quality of life for TSC patients and their families? | * Yes * No * Unsure | |

TSC, tuberous sclerosis complex